Make today a breakthrough.

Testimony of

Hayley McDonald, Cure SMA Supporter
Boise, Idaho

Before the
Idaho Senate Health and Welfare Committee

on the

Implementation of newborn screening for spinal muscular atrophy in Idaho

Chairman Martin, Vice Chair Riggs, and Members of the Committee,

Thank you for again inviting me to speak before the Health and Welfare Committee on Idaho's implementation of newborn screening of spinal muscular atrophy—or SMA.

I am Hayley McDonald from Boise. I am a lifelong Idaho resident and an active supporter of Cure SMA, the leading national organization that represents individuals with SMA and their families.

One year ago, on February 22, 2021, my husband, Bill, and I appeared before this committee to talk about the importance of newborn screening of SMA, a rare neuromuscular disease that that affects the motor nerve cells in the spinal cord, impeding a person's ability to walk, swallow, and breathe.

I shared with you how this devasting disease took our precious little girl, Liv, from us in 2017 at less than 7 months of age. I told you about our joy in bringing Liv home after her birth on March 7, 2017. She was the most beautiful little girl who had the most expressive eyebrows. Her vital signs were normal, and she was released from the hospital following a routine delivery. But within 2 weeks, we started to see warning signs—first related to difficulty in feeding and then because of missed developmental milestones. This began our diagnostic journey that included several doctors' visits and a trip to the hospital. On May 26, 2017, Liv was diagnosed with SMA Type 1, the most common and severe form of SMA.

As I shared with this committee earlier, infants with SMA Type 1 lose 90% of the motor neurons needed for physical strength by 6 months of age. Once these neurons are lost,

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Hayley McDonald